Strategic Planning Across Montana (SPAM) II meeting notes Planning for the future for and with people with developmental disabilities June 8, 2005

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Meeting evaluations summary

<u>Parking lot of issues</u> or subjects to come back to, written on easel paper and recorded here so we don't forget them:

A. Process points:

- For each goal, name the time line and if it's expected to be repeated or continuous in its execution.
- Clump or group the goals by subject or issue.
- Focus on outcomes, not solely specific activities.
- Be creative.
- Refresh our values to include that it's okay to say it would be tough pursuing the goal being proposed or that we're about to make something more complicated than it already is.
- Build in accountability.
- Do a state of the system.
- Create grading criteria for each goal or recommendation. Set up a report card system of accountability.
- Decide how we're going to present what we decide here to the Legislators.
- Name the barriers and how to overcome them.
- Arrange the room in a circle so we can all see each other.
- Decide a decision making process.
- Name the problems we are trying to solve.
- Send the meeting minutes to an interested party list, perhaps those that don't join the group but whom we'd like to be kept in the loop, AND then invite them specifically to the last meeting.

B. Subject/issue points:

- Build capacity for services in the communities.
- Labor pools is a huge issue of concern.
- Other MDC issues.
- Medicaid infrastructure grant to avoid either-or decisions about going to work.
- Encourage the use of natural supports. Incentivize it.
- Create more People First chapters in small towns.

What were the 1998 Plan's overall goals and purpose?

- To see what we could accomplish through developmental disabilities services.
- Managed care created the need for planning. We were thinking about how to save what we had and how to make what we had better.
- Aging kids who have never been in institutions drove part of the need for planning. Kids moving into adulthood and how to make their lives good, beyond being just "kids with furniture."
- There was a real interest in involving the greater community parents and legislators and envision what the system could look like with more diverse input.
- Making the maximum use of limited resources and stagnant dollars, which connected to the community.
- Public awareness for parents and how to go about getting the information to them.
- Specific gaps in needs such as transportation and the needs of senior citizens.
- We recognized the need for better partnership between people who deliver and receive services in identifying needs and supporting people and carrying out programs.
- To address the needs for housing, especially portability, and giving people options.

How was the 1998 Strategic Planning Across Montana carried out?

- It came out of the Montana Developmental Disability Council, with some pre-meetings about who and how. 64 people participated.
- It was a series of five meetings with a facilitator.
- It built slowly and honored the need for good relationships.
- It took on a life of its own.
- The work was done by sub-committees; that's where the work was done.
- It built relationships between people and groups, and those can be re-kindled.
- Committee chairs were chosen.
- There was a broad mix of people and interests, and we were appointed to the subjects we were interested in.
- There were no dumb questions. The self-advocates were confident of the process. It was the first time consumers were fully a part of the process and they were well mentored. We were together to solve the problems. Consumers were encouraged to voice their needs and wants.
- It was great to include rural Montanans.
- Committees met at the meetings, and reported to the full group as the recommendations were developed.
- The changes we recommend from last time the SPAM group gathered:
 - a. Agree who will pursue each goal or activity, and don't assume it's all the Developmental Disability Program at DPHHS.
 - b. Shoot for less arguments and more arguments.
 - c. We took too long drafting the vision statements.

The mission statement, SPAM's original purpose and special function was:

To support Montanans with developmental disabilities in living and working as citizens in their communities.

Today's group suggested adding the word "contributing" before citizens.

The original SPAM Vision Statement, the outcomes they sought were:

A lifelong array of choices for quality family and individual supports which are consumer friendly, flexible and accessible on an equal basis and foster dignity and respect.

Today's group suggested replacing the word "consumer" with "person-centered."

The values named in 1998 were:

- 1. We value the uniqueness of every individual.
- 2. We value dignity and respect for everyone.
- 3. We value equal opportunity for risk and reward, with the right to expect the same things out of life as everyone else.
- 4. We value self-determination and the opportunity to make one's own life choices.
- 5. We value informed choice so that people can select what they need.
- 6. We value individual responsibility and that everyone does what they say will do.
- 7. We value accountability to insure the effective use of community resources, and for individual actions and their consequences.
- 8. We value health and safety with both safe environments and physical, mental and spiritual health.
- 9. We value security, knowing that services will be there when needed.
- 10. We value continuity and stability, including smooth transitions, seamless delivery, and stability in service provision.
- 11. We value creativity in the utilization of all available resources, and innovation in service excellence.
- 12. We value grassroots, locally-based services.
- 13. We value partnerships, mutual respect, trust, open communication, honesty, equality and collaboration.

What do we hope to accomplish by doing SPAM II? What results are we hoping for?

- Establish a unified vision and goals. Without goals we'll never reach them.
- Build the capacity of communities.
- Incorporate new, progressive approaches.
- Improve the quality of life for people.
- Address the heavy strain and huge issues the system faces.
- Provide supports to people.
- Address a community-focus of services.
- Help the system become more simple and user-friendly.
- Name the worries; take our time; do the problem solving.
- Address funding concerns.
- Make sure we hear from people with developmental disabilities, their advocates and families. Insure they understand and have a voice in our proceedings. One way to go about it is to avoid abbreviations and acronyms and esoteric terminology.
- Create a united product.
- Figure out how to coordinate with mental health crisis intervention providers.
- Address whether we need an institution.
- Dream big dreams, be creative; think outside the box.
- Look at ways for families to administer their own funds.
- Make new service options and approaches available the communication/conduit piece.

– Use our money effectively - at the right time and at the right time.

What issues do we hope to address and problems do we hope to solve?

A. Self-determination:

- Early intervention.
- Individualized supports.
- True retirement choices.
- Meaningful employment.
- Transportation is available!
- Voting.
- Options are explored and chosen based on education and informed choices.
- Post secondary opportunities.
- Portability of services between communities; get the services wherever you choose to live.

B. Community capacity:

- Utilize and develop local resources and volunteers.
- Staffing pool issue and crisis.
- Insure services are available for individuals with severe and high risk behaviors.
- Include the Olmstead Decision and others into everything we do with services.
- Build effective linkages (no more "transition" language) between schools and after school.

Make it seamless and less fragmented.

- Transportation.
- Uniform education and credentialing for direct support professionals.
- Dwindling pool of potential future employees.

C. Community life:

- Early intervention.
- Quality of life, regular access to the community.
- Ensure there are processes in place for protection of choice, safety and dispute resolution.
- Ensure quality standards are met, beyond the minimum standards.
- More people move out of group homes and live on their own independent or supported.

D. Support:

- Early intervention.
- Integrate students into classrooms.
- Decrease the waiting list.
- More case managers.
- Individualized supports.
- Unpaid advocates.
- Mental health services for people who are dually-diagnosed.
- Provide short-term crisis intervention services.
- A simpler system, with more flexibility and possible creativity.

Who else shall we invite to help with this planning process?

– People with developmental disabilities. Colleen can help. Consider Quality Council members and People First presidents.

- Parents of children with developmental disabilities. Consider those with children of a variety of ages to insure we have at our table those that are new to the system to those that are battle-tested.
- Friends of people with developmental disabilities.
- Medicaid.
- Legislators: Holly Raser from Missoula, Carol Williams from Missoula, Christine Kaufmann from Helena.
- Mental health system representative DPHHS Mental Health Division representative.
- Office of Public Instruction.
- A teacher from the Council on Exceptional Children.
- PLUK (Parents Let's Unite for Kids).
- Rural Institute.
- Physician.
- Legislative Fiscal Analyst.
- Governor's budget person.
- Direct care staff.
- A transportation provider.

Next steps: METNET meetings statewide and our next meeting

A. Local meetings will be conducted to identify the problems and issues to be addressed, and the solutions recommended by people all over the state. They will last an hour to an hour and a half, followed by downloading their suggestions to the group via METNET.

This will be done, town-by-town, with each community reporting into the Helena METNET site one at time. Only Helena's METNET site will see and hear the report from each community. The date for this leap-frog meeting will be a day in September to be determined by METNET's availability.

- B. The whole statewide group will meet in Helena on Tuesday, October 11 from 10 AM to 4 PM.
- C. A work group was appointed and volunteered:

Jack, Colleen Nichols, Deb Swingley, Jeff and Jackie, and Steve from Montana Advocacy Program.

They will look at possible revisions to the mission, vision and value statements, the name of the other group, generating attendance at the METNET meetings in September and prepare for our October meeting.

Progress report on the 1998 SPAM recommendations

- 1. Increase appropriation for expansion of services,
- 2. Provider rate increase;
- 3. Direct care staff salary increase;
- 4. Funding for transportation; and
- 17. Continuation of the early intervention (Part C Entitlement)

Jeff: There has been a significant increase in Medicaid and a significant decrease in general funds. Most of the dollars are passed through to service providers in communities. Some increases came from the Legislatures and the I-149 funds, and for direct care staff pay increases, over the last few legislative sessions. See the handout that was provided about those allocations over the last few years.

We made the choice a few years ago to move everyone possible into Medicaid, from \$25 million to \$44 million between 2001 and 2006. The general fund expenditures, meanwhile, have gone from \$32 million to \$28 million. Our match is general 29% general funds and 71% federal funds. That is going to change; we're expecting a 2% cut each year in federal funds. As the Montana economy improves, our ratio (FMAP) from the feds goes down. Title 20 cuts are also expected.

The Developmental Disabilities Program has expanded funding quite substantially. Part C early intervention, an entitled program, equals about \$5 million for children.

Federal legialtive authority used to be given to the Division; now it's given to the Department. It means you are authorized to spend federal dollars, and we've never had a problem getting it.

Bill: The take-away is the increase over the last 10 years is mostly about taking people out of the 100% general fund, and put them into Medicaid, while we experienced tiny increases in state. It allowed us to expand services to three times as many people.

Joe: Since 1998, the demand is just as strong, if not stronger than it was then. We still fund people with general fund dollars. Over those years, the Department of Public Health and Human Services has grown to the billions of dollars, with a large spotlight on it. This next legislative session the focus will be on mental health and Medicaid. Greg hit on this early on about continuous efforts; our waiting list has not changed. Our waiting list of developmental disabled eligible people is 1,277 people.

One of the battles I fight is about people being entitled to services and case load growth. DD is an eligibility issue, not entitled, so case load growth is not automatic. This issues is not going to go away.

Bill: Regarding recommendations 1 through 5, we had a wonderful collaboration with the providers regarding staff pay, sick leave, costs of services. Now we have tremendous information so we can go way beyond direct care salary increases. Now we can go beyond and think of different ways of doing things.

4. Funding for transportation

Deborah Swingley: The Council wrote the Montana Coordinated Transportation Handbook. The Department of Transportation is handling the current 5310 providers, to help consolidate and coordinate use of existing vehicles. The whole plan is available at www.mtcdd.org. Also a transportation coordinator has been hired – Marlene Disburg, who works hand-in-hand with the Department of Transportation.

Jeff: We're reimbursing at \$.30 per mile and realize it doesn't even cover the costs of operating a vehicle.

What are the EPP priorities for new dollars this year? Jeff: The #1 priority is the rebasing effort to request an increase dollars to providers, an increase of \$6 million general fund, for a total of \$18 million of new dollars to providers. The #2 priority is to decrease the waiting lists, particularly kids who are aging out of services. They are partially funded right now and the money would also be used for moving people off the general fund waiting list at a rate of 50

individuals each year. The EPP process stands for the Governor's Executive Planning Process and includes requests for inclusion in the Governor's budget, a proposal that goes to the Legislature.

Charlie: It is exciting that the Department has made it the priority it has. The data and analysis explains the rational behind the request, versus saying we need it. Now we have a tangible rationale and data which will give us a leg up at the Session.

6. Protecting people at Eastmont

Jeff and Cathy: Eastmont closed in December, 2003. Some individuals moved to the community in Glendive; others moved to the Montana Developmental Center (MDC). (Only one remains there today.) See the orange handout about the MDC census statistics and trends. At the end of the year, the census at MDC will be 70. An issue is that MDC can't control whether folks come to the Center. DDP does it's best to help maintain people in their community settings. We really have a challenge ahead of ourselves. The population left there is a tough crowd; they are hard to place in communities because of difficult behaviors. We refer people right now to community services, but it's very hard to find a provider who will take them, has the space, and the infrastructure to support their behaviors.

7. Lifespan respite

Two agencies, STEP and DEAP provide this service. When the grant ended, United Way funds, in part, have made it possible to continue the services. Both programs are alive in both communities. There is group working toward federal funding. One effort in Helena was dismantled.

Some state funding, \$40,000, was provided. It provided hubs for resources for both people who are elderly and people with disabilities. There are good partnerships with Senior and Long Term Care.

Charlie: All of DPHHS is looking at this model and characterizing it as care giver support – which will be a broader service to include more than just respite for the primary care givers.

8. Family Involvement Policy (FIP)

The Family Involvement Policy was finalized in January, 1999. See the handout that was distributed. It is practiced to this day. DDP and providers include family members on Boards, Councils and committees.

Have there ever been surveys done with families about services? Yes, regarding satisfaction at IP, special ones, but not a grand one statewide with families using services. The last one was the CORE Indicators Project in 2000.

9. Arrangement of medical and other care prior to new placement.

It's not part of the screening rules. In practice, it's not part of screening, but it is in transition services. No screening rules changes took place. Include it during placement.

10. Crisis intervention teams and facilities

Jeff: There are no formal crisis teams. We have made the Montana Developmental Center's staff team available to communities across the State for consultation and it's been very successful in preventing crisis admissions and provide consultation and training.

We have crisis funding and discretionary funds. We can provide adaptions to a home, for instance. We create additional funds for short-term, not longer-term, to the tune of \$.5 million to sustain people in the community. It is allocated on a regional basis.

We trained all our QIS's and providers and families in applied behavioral analysis to help with crisis stabilization and our direct care staff on behavioral and health care subjects. Ongoing training is not a requirement of providers; a work group is addressing this need. We've also studied what's out there for people in crisis. Not a lot exists other than the Montana Developmental Center. Mental health crisis facilities are being developed and we're creating the understanding that they can serve our population too. A Helena group is seeking funding to open one; DDP has pledged funds to help with the project; they hope to expand the program to other areas across the state. Kalispell has a respite house. MANDT training has also been good.

11. Design and implement an effective transition from school to work.

Tim Harris from the Office of Public Instruction: No transition specialists have been placed at the 23 field coalitions as we envisioned in 1998. In 1997-1998, most kids between 19 and 21 years old received services. Now when you're 19, your IEP services end.

In secondary to post school course work, a Vocational Rehabilitation course was recommended. We haven't heard that has happened, but workshops do exist for all the teaching students. We are improving, but still have a long way to go.

12. Employment and business development

Jeff: I don't know if we ever did a grant like the recommendation names. Joe: Our Blind and Low Vision got their program up and successful doing a vending route business. Jeff: We have a lot of work regarding self-employment. Some are successful, some have not been. We've worked with the Department of Commerce and the Rural Institute. There are probably more opportunities now than when the plan was written.

Supportive employment is going strong. We can tell many stories with successful outcomes. Self-employment is a requested direction. We need to address what supports need to be in place.

We received a Medicaid Infrastructure Grant to look at incentives and the dis-incentives of people going to work such as losing health insurance. We are looking at Medicaid buy-in so people can keep their Medicaid as their health insurance. Right now it's a either-or choice. We're excited about this.

13. Supported retirement. SPAM recommends that individual planning teams develop a plan of supported retirement for individuals who are appropriate for retirement.

Jeff: We have 102 people in a supported environment. Also as part of our waiver program, we will be offering an assisted living service for elderly or elderly-like people with developmental disabilities which starts July 1.

14. Public awareness

Deborah: The Montana Developmental Disabilities Council did a poster contest for 10 years. For the last year we supported the play called "Same Difference;" it's been our biggest push for public awareness. We are contemplating funding them again. We partner with Helena Industries for Disability Awareness Month and others to put up billboards regarding disability awareness.

A Council member recommended a postage stamp which has to start at the Congressional level. Daphne: Does the choir still exist in Missoula? Yes.

15. Teacher preparation

Tim Harris: We're still looking for more courses. The Rural Institute does provide a packet of information for people currently teaching. Our recommendation was to provide an overview, via a course, of exceptionalities.

16. Developmental of natural resources and supports

Tim: There are two major areas of activities:

One: Community supports program was designed to provide individualized services to individuals to encourage the independent living of their choice. The funding is portable and folks can receive the supports where they choose to live.

Two: Personal support planning process that will replace the current IP system. It has involved a large stakeholder workgroup to look at current IP systems, its strengths and needed improvements, and made a series of processes, procedures and forms that were field tested and is now complete. It is being tested in Region 3 before statewide implementation. It is personcentered planning, with no dictating about the person's needs. This is a whole new way and powerful way of doing things. It's really about what people want and not what we want. How does it work? People are encouraged and supported in living, working, playing and retiring and make their own choices. It's all about the person. They determine the supports and services they need and want, and will know how much money is available to them.

17. See #1 above.

18. Home investment/ownership.

Michael O'Neill from AWARE and the Home Choice Coalition: Home ownership for people with disabilities gets better every year; success breeds success. Eleven people have become home owners and 30 families have been assisted. \$650,000 in home ownership resources are now in control of people with disabilities, which creates autonomy and independence and many other personal benefits. We are mainstreaming people with disabilities into programs that help people with home ownership with a variety of tools. Silent second mortgages are provided with money that recycles forever at 0% interest, only payable when they sell the house. Eventually it becomes a self-sustaining cycle. An equity-sharing element will be added in the future.

19. People with disabilities helping families.

The Plentywood project is still going strong and self-sustaining after the Montana Council on Developmental Disabilities' (MCDD) initial funding. Employment as part of system change is one of the four top priorities for the MCDD Council.

20. Individualized supports. SPAM recommends providing and/or facilitating individualized life supports for all current and future supported living consumers.

See the orange handout.

21. Funding for People First

Deborah: We are so thrilled with the growth of People First. There are 340 members in 16 chapters. In addition to MCDD, there has also been support of People First by MAIDS, the state Developmental Disabilities Program, and the Rural Institute. "Licensed to Independence" is a pilot program from Missoula, and has moved across the state in a very exciting way.

The MONA Monopoly conference was conceived by People First and the Council looks to their leadership. The People First national Conference was two weeks ago and Montana sent 4 people, thanks to the Montana Advocacy Program. Three chapters are self-funded.

There are two goals: Increase the function of People First as advisors, and find additional funding.

22. Prevention of abuse and neglect.

See the orange handout.

Our quality assurance has been so well received by the Center for Medicaid Services (CMS) they recommend it to other states. Each provider is reviewed extensively utilizing three techniques – observation, interviews and a documentation review.

Meeting evaluations summary

- 1. What was the *most* productive or helpful or interesting parts of the today's meeting?
- Once we got to the interactive part.
- Renewal of our hopes for the system.
- Brainstorming the future of SPAM.
- Review of where we were (1998) to where we are, and identifying what still needs work.
- The guidance, lists, etc. kept it to the point and productive.
- Pretty much all of it.
- Hearing about what we have accomplished and what we want to accomplish in the future.
- Discussing what each person cares about specially.
- Getting things straight and dong what we are supposed to do.
- The facilitator thank you Beki.
- Hearing other people's perspectives on issues.
- Having someone to keep it moving and focused.
- Kept group on task.
- I really enjoyed listening to the concerns of parents and providers.
- Review of progress on old SPAM goals.
- All. Beki kept it on track!
- Facilitation. Encouragement to participate.
- The facilitator staying on course. Good job.
- To know what came out of the first plan. To know we made a difference.
- Open, receptive discussion.
- Helpful.
- 2. What were the *least* productive or helpful or interesting parts of the meeting?
- Reports from the state staff.
- People having to leave early.
- Was well run; good use of time.
- Great job across the board.

- None.
- I got lost on the acronyms, etc. and complex detail at times.
- Filling out this form!
- Don't know. Too soon to say.
- Time went by too fast! Need extra time to discuss a lot of issues.
- Some frustrations it's a big picture.
- Not exactly hitting tyres at hand. (or types? Beki can't quite read this. Sorry.)
- All facets were productive, helpful, and interesting.
- Listening to DDP staff talking about things I've heard many times before.
- Lunch, and presenting progress, but that was more reporting in nature anyway.
- -???
- I believe it was successful. I don't see any negative.
- 3. Did you *accomplish* what you wanted to accomplish? If so, what subjects or issues or topics were they?
- -B+
- Yes.
- Yes!
- Planning for where to go next.
- Yes, I expressed my three main concerns and they were recognized.
- My attendance today was for follow-up. Someone else will be in my place as it progresses.
- Yes, my concerns/issues/topics were included in the big list.
- Yes.
- Agree not to argue during the process!
- Yes. Because acquainted with others. I was able to voice my concerns. Good attention to DD issues.
- Yes ??
- Yes, update to original recommendations and a plan for where to go next along with a method.
- Not sure I've accomplished anything, yet.
- Included needs for community services for high risk and severe behaviors.
- Focus for future meeting.
- Yes.
- Yes, the issues I wanted were addressed.
- The process is just beginning, but it was a good beginning.
- Bringing up the importance of voting.
- 4. What *changes and improvements* would suggest for our future meetings?
- **-**?
- Well done.
- More parent and provider input. More balance in the participation.
- Don't have any.
- None.
- Nothing.
- More time.
- None.

- Need to look at whole structure of services to address need for MDC in the future plan of services.
- Works for me.
- Being able to see each other. Arrange room so people don't have to turn backs on each other.
- 5. What would you like to have left exactly as it was today? Keep these characteristics:
- How things moved smoothly.
- Good facilitator!
- Time frames.
- Beki is a good facilitator. He knows when to move it along and when to cut it off.
- Leadership, lists, to the point.
- Let others determine.
- Everyone was able to give input.
- Too soon to say.
- Facilitator and format.
- Giving everyone an opportunity for input.
- The name.
- Open discussions. Setting agenda and sticking to time frames.
- 6. Any *other* feedback, comments or suggestions you would care to make?
- Perfect! Appreciated keeping on time frame!
- Go for it.
- Great facilitator. Beki was able to keep the group on track.
- Nice job facilitating, kept us on task, and positive, with humor.
- The METNET concept should be a PART of the information gathering process. Want more ideas? Call Perry at 444-5662.
- Some discussion of how the group decisions will be made.
- Great job Beki!
- Very interesting. Thanks.